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The Stories that Unite Us: Socialization and Inclusion of Adults with Intellectual Disabilities (ID) Through Library Book Clubs

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Abstract: This study describes a book club for college students with intellectual disabilities (ID) at Florida Atlantic University (FAU) and its implications for serving adults with ID. This population is defined as an individual with an IQ of 75 and below who has problems with communication, self-care and socialization. This group is part of a larger category of intellectual and developmental disabilities (IDD) which include physical problems such as limited physical mobility created due to conditions such as cerebral palsy. Intellectual disabilities are usually diagnosed before the individual reaches the age of 18.

Keywords: Inclusion; Adults with Intellectual Disabilities; Library Book Clubs

Knowledge Focus: Best Practices; Advocacy/Activism Focus; Project Focus; Research/Theory Focus

Topic: Disability Studies

Issues for Adults with ID

While adults with ID have been successfully integrated into the public school system through extensive legislation, nothing has appeared to support them after. This relegates them to loneliness and deprivation which can reverse the gains of their education. Libraries are one of the few social institutions providing access to individuals with ID, and it makes sense to start with them in developing additional opportunities. The library profession has recognized this need for some time. The American Library Association's (ALA) Bill of Rights, promulgated in 1939 to recognize the 150th anniversary of America's Bill of Rights, demands that libraries support all patrons without regard for degree or type of disability. Yet libraries lack training for special education and struggle with resources for their core functions. Moreover, the defining condition creates significant barriers to the reading services that are the library's essential mission. Libraries are left with a conundrum. In the quest for diversity and social justice, it is imperative for libraries to support individuals with ID, but there seem to be overwhelming barriers in the way. Similarly, there is a pressing problem for individuals with ID who lack any support beyond

their public education. For both this population and the library profession, there is great urgency and much at stake in solving this problem.

Previous efforts by libraries have not been successful. These include outreach to draw individuals with ID into libraries; specialized collection centers of material judged suitable for reading and for relatives to advocate for them; and a global overhaul of library services to make them completely accessible to individuals with ID. Efforts in these directions have required vast resources with little results to show. Libraries have failed to connect in a natural and sustainable way with the needs of this population.

Grass Roots Initiative

To circumvent this issue of limited opportunities for adults with ID, a grassroots initiative known as the Next Chapter Book Club (NCBC), was developed by Dr. Tom Fish, Director of the Ohio State University's Nisonger Center for Excellence in Developmental Disabilities. The organization provides informal book clubs that offer reading and socialization opportunities for adults with ID. What began locally in Central Ohio has now spread throughout the United States and overseas under its own initiative through social media. Currently, there are 250 such clubs in North America with an additional 60 in Europe. Approximately 60 clubs in the U.S. are affiliated with public libraries. They are fairly new, having formed within the last seven years, and are largely concentrated on the East Coast. It is also worth noting the achievements of the oldest public library club for individuals with ID which has followed a completely separate line of development. In the early 1980s, long before the rise of the NCBC, children's librarian, Miss Mattie Rials of McComb Public Library in McComb, Mississippi, developed a club for adults with ID. This group is called the Wednesday Friends for the day of the weekly meeting, and they participate in social and educational activities engaging in crafts, singing and attending guest lectures. Rials continues to run the club more than 40 years later. Her success can be attributed to her status as a pillar of her small southern community. Her presence is so influential that all of McComb pitches in to support Miss Mattie's efforts to offer inclusion for adults with ID. The close integration of the club with the community is a look ahead to what library clubs for adults with ID might be able to achieve in the future.

PSE Programs

Academic libraries may become available to adults with ID through Post-Secondary Education (PSE) programs which provide educational opportunities for them at college campuses. One useful resource is the ThinkCollege manual and website, which lists and describes the curriculum for 131 four-year PSE programs. The majority of the student enrollments are small averaging between 11–20 students in each. Most of the PSE programs offer courses that can be audited, yet some curriculums are modified to match the abilities of the students. Most of the courses offered focus on teaching vocational and life skills. Preferred activities usually include sports and recreation. The majority of PSE programs are located

throughout the Midwest, the South and on the East Coast of the US with others scattered throughout the West Coast. When reading about the programs, it was noted that no mention of a library connection could be found for any of them.

Educational Theories

NCBC represents one new approach which circumvents the whole question of reading instruction by combining reading and socialization together in an informal manner. Its success may be explained partly through a sea-change in special education. Older systems that involved teaching individual words and syllables and extensive drills were found to be unsuccessful. In their place, special educators have begun teaching context-based meaning. The most immediate context is the story. Rather than building meaning up out of components, students learn through relationships within a narrative. This method is more challenging for the students but also offers greater incentive and appears to be more successful. Context can also refer to the learning environment, alternative learning styles and even fellow-learners. This development underlies the third theory: Universal Design for Learning. This theory emphasizes the importance of alternative learning styles to the learning process and seeks to accommodate as many as possible. These three developments explain a good deal of the developments we have surveyed as well as the case study we have conducted at FAU.

Case Study

The case study featured in this presentation is a book club that began in an academic library at FAU in Jupiter, Florida. The academic librarian who coordinates the club thought of the idea after being approached by a faculty member in the Academy for Community Inclusion (ACI) at FAU. The ACI is an example of a PSE which began during the spring of 2016. This grant funded program's first cohort had only eight students enrolled, and has since grown to a current enrollment of 35 students. There are three certificate tracks that the students can take which include supported employment, supported community access, and supported community living. Each certificate track is worth 20 credits. Students have the flexibility to design their course plan to include working towards all three tracks if that's what they choose to do. In addition to taking courses to fulfill these certificates, the students must take two pre-requisites and electives, one of which must be taught outside of the ACI curriculum. Taking electives outside of the curriculum provides a unique experience for the students and enables them to attend classes with their typical peers. The program's primary goals are to foster independence and provide the students with job skills so that they can one day hold down paying jobs. The ACI is an example of a hybrid program as outlined in the ThinkCollege book and website. Students are learning side by side with their peers who have intellectual disabilities, and they are integrated into courses with typical college students.

In Spring 2016, the first book club at FAU was held, and an average of 13 students attended on a regular basis throughout the semester. The mixed group consisted of students of

varying ages and reading abilities. Over the last three years, the book club has grown so much in popularity that the club now meets during the summers and has increased its meetings to twice a semester to accommodate the students' schedules.

To plan the club, the coordinator consulted the NCBC's older manual which has since been revised. She followed the NCBC guidelines to create a reading experience that would appeal to adults with ID regardless of their reading capabilities. The coordinator experimented by introducing a variety of genres into her club sessions. The first book the group read was the young adult chapter book, *Hoot*, written by Carl Hiaasen. The book was chosen for several reasons, namely because it took place in South Florida and one of the plot lines involved saving an endangered species, the burrowing owl. Continuing in the same vein, the second book chosen was another young adult chapter book, *Stryder*, written by Beverly Cleary. *Stryder's* storyline involves a stray dog and the boy who befriends him. Interestingly enough, *Stryder* did not resonate well with the group, and there could be several reasons for why. One possibility is that it discussed more mature themes than the audience could understand. Additionally, the main protagonist was a young male and most of the club members at that time were female. Throughout the semesters, the facilitators used a combination of the following formats which include young adult chapter books, picture books, children's literature, short stories, poems and biographies. Some of these formats were popular with the group and others not so successful. The coordinator noticed that typically the shorter chapter books, or Disney Jr. novelizations based on popular Disney movies, were favored over longer chapter books that had more mature and complex themes. At one point the group tried reading a book of poems which the coordinator thought would go over well due to the brief text and the beautiful illustrations, but this too failed, likely because the concepts were too abstract. One surprising find was how much the group enjoyed reading the biography of J.K. Rowling, the author of the Harry Potter series. When the biography was suggested, the facilitator was skeptical. Instead, it was a great hit! All of the students knew of and had read or seen the Harry Potter series. They could especially relate to the fact that J.K. Rowling had experienced numerous rejections before her story was published. This story of facing failure head on and persevering to succeed resonated with the students.

Regardless of whether the material was successful or not, reading for an entire hour proved to be tiresome for the students. Due to the varying reading abilities of those in the group, with some members being more advanced readers than others, the facilitators decided to split the one-hour sessions into 30-minutes of reading followed by 30-minutes of game playing or some sort of educational activity. Club facilitators used a variety of games including board games and often modified the games to suit the group's needs. Some examples of games played and educational activities completed include, Pictionary, Charades, word searches and crossword puzzles, Bingo, Hangman, question/answer games, and movie and book related trivia. Certain games were more popular than others. Pictionary and Charades were usually successful whereas Bingo and word searches hardly interested the group. The coordinator realized that any

interactive game such as Pictionary, or Charades which required the group to get up in front of one another to either draw or act, was successful. More solitary activities such as Bingo or a word search fell short.

Assessment

To assess the book club, the authors first examined attendance as one of the few forms of objective data available. Attendance was examined for various measures: literal attendance of the students, persistence during the club, and retention or return for future book clubs. Persistence turned out not to be meaningful as student attendance remained constant throughout the semester. Sixty to eighty percent of those enrolled would reliably attend during a semester. Forty percent would return for 50–100% of future book clubs, while the remaining 60% would not. These results roughly correlated the findings of surveys that the authors distributed to 30 of the 60 NCBC clubs registered with public libraries nationwide. With this attendance for an elective activity with no credit or author incentive, we consider the book club activity viable.

Behavior Codes

To evaluate activities within individual classes, the authors developed a scheme of behavior codes. Repeated behaviors that clearly expressed the degree of attention to the activities that were identified. Then they were sorted into three categories signifying different levels of engagement. For example, behaviors that were perceived as supporting the desired goals for book club, meaning positive socialization, would include full engagement in the reading, game playing, and educational exercises. Supporting one's peers while reading, and participating in reading aloud were other behaviors deemed positive and in favor of the book club's goals. Behaviors that would be characterized as unsupportive of book club goals would include distracting behaviors such as talking off topic or monopolizing the conversation. Finally, isolated behaviors such as playing on one's phone, falling asleep, coming late, or taking a snack and leaving would be characterized as behaviors that do not support the socialization goals of book clubs.

Coding proved to be a difficult endeavor because the interactions amongst the group members is fluid and at times chaotic. Other issues faced included scheduling conflicts for the facilitators. If a facilitator needed to miss a club session, the club coordinator would have to fill in and code while trying to run the club. The coding results support the fact that participation for reading and playing games was greater than either socialization or isolation. But it was impossible to relate the students' reactions to individual readings or activities. For additional assessment of the session content, the facilitators used field notes which are the basis of the assessments above of individual readings and games.

Surveys of NCBC Public Libraries

With permission, the coordinator was able to acquire a list of 60 chapter affiliates in public libraries throughout the United States. She contacted them through email and requested a phone conversation to ask basic questions about the facilitation of their clubs. She was surprised to find that almost everyone was willing and eager to oblige. Phone interviews were set up and a survey of nine questions was asked of each club facilitator. For those who could not schedule a phone call, the survey questions were sent via email and answered electronically. Out of 60 clubs contacted, 30 responded. Most of the survey findings mirrored that of FAU. Namely, the clubs measured success by attendance, retention rates, and their perceived engagement in the sessions. In accordance with the guidelines of NCBC, the clubs emphasized socializing along with their reading. Some clubs provided planned activities such as outings to movies and restaurants or holiday parties; others kept the club sessions in-house. Some clubs incorporated crafts and educational activities focused on learning new vocabulary to supplement their reading. But the academic library club at FAU was the only one to use games extensively.

Surveys of Parents and Students

Other means of assessment were conducted via a survey administered to the students and their parents/guardians. Thirteen student surveys were administered. The members were asked their opinions on the book club. The facilitator wanted to know whether or not they enjoyed their participation in the club and their plans for future attendance. Student responses were overwhelmingly positive and indicated that they enjoyed their involvement with the book club and intended to continue attending.

Surveys were sent to six parents whose sons or daughters were repeat members in the book club. The survey questions were designed to assess any observations they had regarding participant satisfaction and whether or not any changes had been noted in their levels of interest in reading or methods of socialization. Three parents responded to the surveys, and all expressed strong satisfaction and high compliments to the club. Two also noted improvements in their daughters' socialization, an increased interest in reading and improved reading skills.

Conclusion

Hosting book clubs for patrons with intellectual disabilities is a low cost and effective option for both public and academic libraries. By providing opportunities for inclusion, libraries are fulfilling their mission of offering services for diverse populations.

Authors



Matthew Conner, Ph.D., has a Ph.D. in American Literature and an MLS. He is the author of *The New University Library: 4 Case Studies* (ALA, 2014) and is the former president of the Librarians Association of the University of California (LAUC). Currently, he works as a librarian at the University of California, Davis.

Image Description: Photo of Matthew Conner



Leah Plocharczyk has an MLS and an MA in Sociology, currently employed at the Florida Atlantic University Library. She is active in mentoring students, leadership and library outreach. She has published articles on library collaboration with marine mammal stranding networks and conflict management within libraries.

Image Description: Photo of Leah Plocharczyk